

Preparing for the Journey

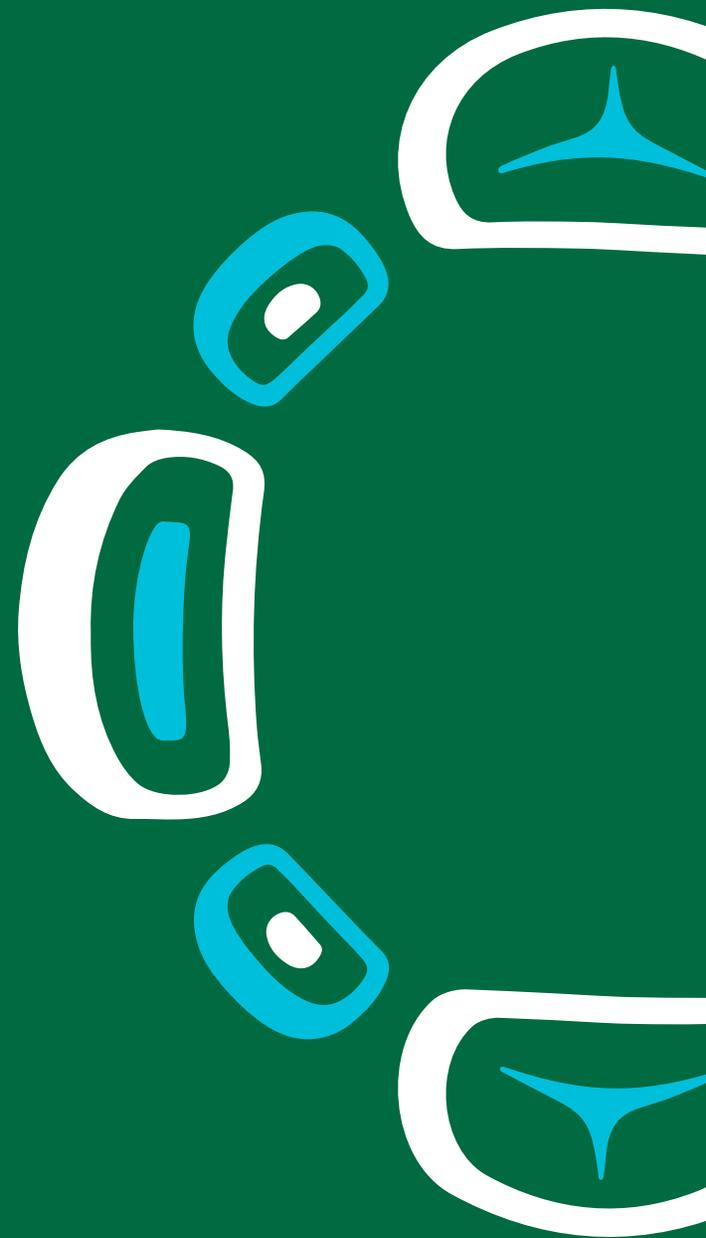
**Wholistic end-of-life care
for First Nations people
living in BC**



First Nations Health Authority
Health through wellness

**BC
CAN
CER**

Provincial Health Services Authority



Acknowledgements



We raise our hands and gratefully acknowledge that this resource was created on the land of the unceded and traditional territories of the First Nations people in BC.

This resource was developed with generous funding support from the Canadian Partnership Against Cancer.

Thank you to all of the contributors who made the creation of this resource possible and a special thank you to the respected Elders, knowledge keepers and community members who kindly shared their experiences and words in support of this resource:

Elder Emily Henry, Ochapowace First Nation
Elder Jo-Anne Gottfriedson, Secwépemc Nation
Elder Mike Kelly, Shxw'ōwhámel First Nation
Elder Theresa Pointe Campbell, Musqueam Nation
George Jefferies, Tsimshian and Gitksan Nations
Lucy Barney, T'it'q'et Nation
Nola Jeffrey, Tsimshian and Coast Salish ancestry
Rachael Alexander, Tsal'alh First Nation

This booklet was developed to support people with a serious illness or life-limiting diagnosis and their friends and families. This resource offers culturally grounded health information about living with a serious illness and thinking about and planning for the end-of-life.

This booklet aims to provide information to support end-of-life care decisions, including options for connecting with services and for advancing wholistic wellness.

This resource is available for download online at [FNHA.ca/cancer](https://fnha.ca/cancer).

For access to additional online resources, please use the following QR code:



Trigger warning

This resource may bring up your own experiences, thoughts and feelings about death and could be triggering. You may need support to help process your emotions. For crisis support, please contact the KUU-US Crisis Line at 1-800-588-8717 or visit the First Nation Health Authority's (FNHA's) website for [additional support services](#).

Contents



What is palliative care?	5
Understanding your options	11
Your wellness	18
Cultural and spiritual supports for palliative care	27
Palliative care supports for you	32
Health, financial and personal planning	38
Personal grief and loss	46
Talking with children and youth	52
Being a caregiver	58
When the end-of-life is near	65
Summary of resources and contacts	71



Before European contact, for the Indigenous peoples of North America, the concept of life and death was a natural part of living. Though our people's beliefs, traditions and customs vary from Nation to Nation, a shared philosophy is that death is just a doorway into the next world.

Some believe they rejoin their loved ones who journeyed before them to the spirit world and shall sit at their ancestral fires. There was also a belief in the strong connection between our ancestors that journeyed onward and those of us still residing in the physical world.

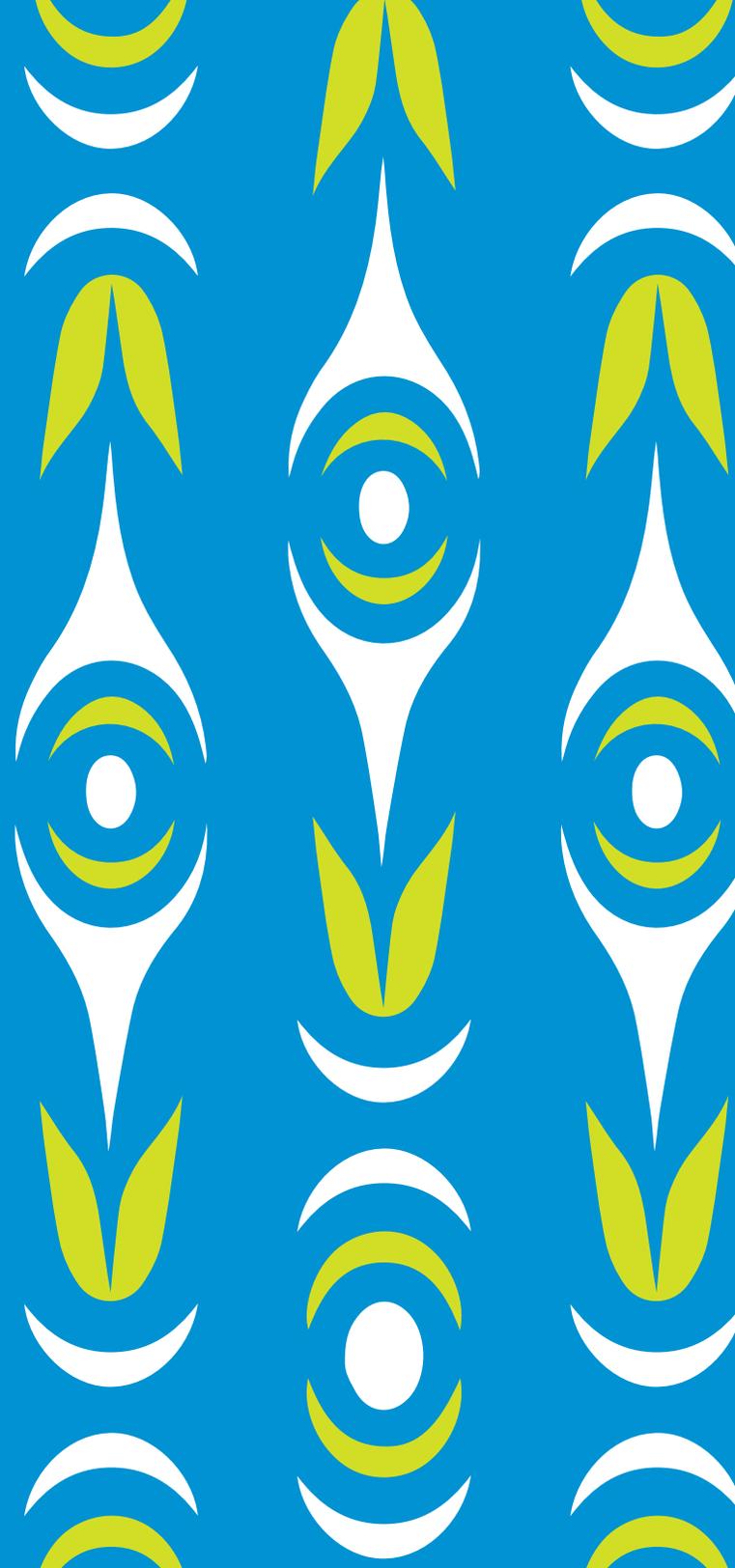
Many ceremonial processes were involved in commemorating our dead because we believed they were close by and still play a vital part in our life and culture. In this light, though there was sadness in leaving the physical world, there was also joy in entering the spiritual world. Many believed that death was the most sacred journey of all.

The understanding that certain traditions will take place before and after death was an excellent source of comfort for the dying person, the family and the entire community. The traditions around death and dying made it a natural part of life.

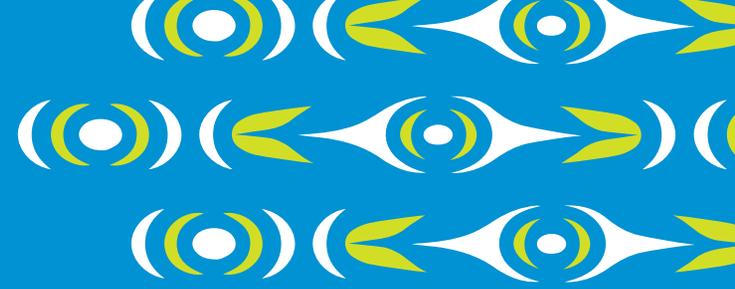
- ELDER EMILY HENRY, OCHAPOWACE FIRST NATION



What is palliative care?



What is palliative care?



Palliative care is an approach to care that seeks to improve the quality of life of people who are living with a serious illness and nearing the end-of-life. The goal of palliative care is to provide relief from suffering, affirm end-of-life as a part of the life process and support people to live as actively and comfortably as possible. Palliative care also aims to support the family and loved ones of someone nearing end-of-life.

The palliative care team is a team of health workers identified to support your needs. In addition to your primary care provider (doctor or nurse practitioner), the palliative care team may also include Elders, traditional healers, traditional knowledge keepers, specialists, social workers, mental health workers, community nurses, home support workers and others.

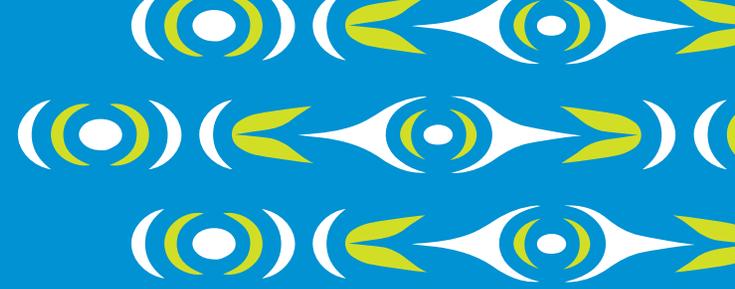
You can start talking with a palliative care team early and during any treatment to talk about what your needs are. The type of care you want and need might change over time and your team is there to work with you to create a plan for your care.

Palliative approach

Aims to provide comfort and improve quality of life through whole person-centered care.

End-of-life care

Focuses on increasing care and meeting the goals of people within their last hours, days, weeks or month of life and their families.



Living with a serious illness

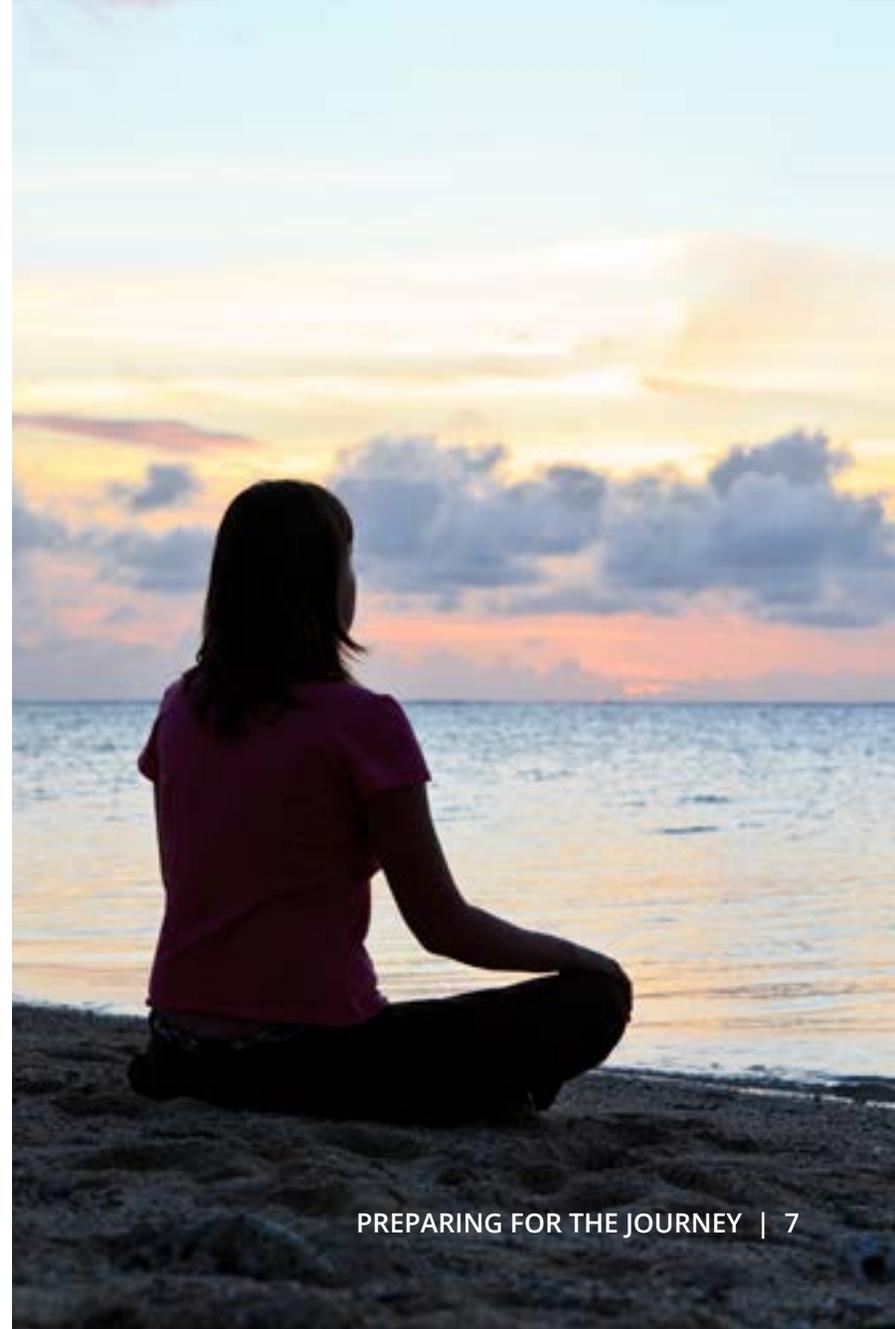
When you learn that you have a serious illness, you may experience a variety of emotions. If you are comfortable doing so, it may be helpful to talk about how you are feeling with a health care provider or friend. Understanding your illness will help to prepare you for the journey ahead.

A trusted health care provider can share information about what to expect when living with a serious illness. Ask as many questions as you need to.

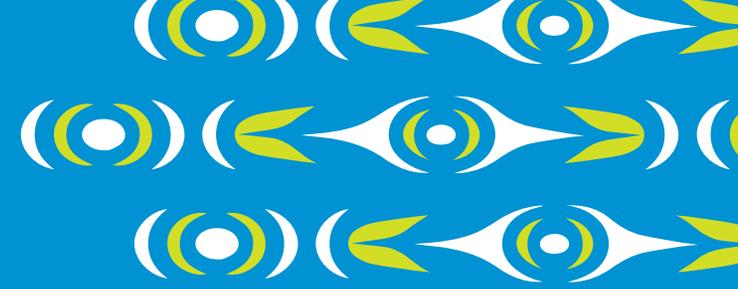


Your final journey is a natural process and you deserve to be blessed.

- JO-ANNE GOTTFRIEDSON,
SECWÉPEMC NATION



Wholistic wellness



Wholistic wellness refers to the interconnectedness of the physical, mental, emotional and spiritual aspects of ourselves and our health (i.e., the whole person). We are truly well when we feel balanced in all of these aspects.

Wholistic palliative care

When palliative care is wholistic, it honours the physical, mental, emotional and spiritual elements of your health. It focuses on your needs at home, with your family and in your community. Both western and First Nations, Métis and Inuit medicines, practices and ceremonies can support your wholistic wellness.

The availability of services may vary by community and region, and access to some services might also depend on what types of extended health benefit coverage you have. Different services may be offered by different Bands, Nations, health service organizations or other organizations.

Talk to your health care provider, regional health authority, First Nations health facility and benefits provider to learn more.

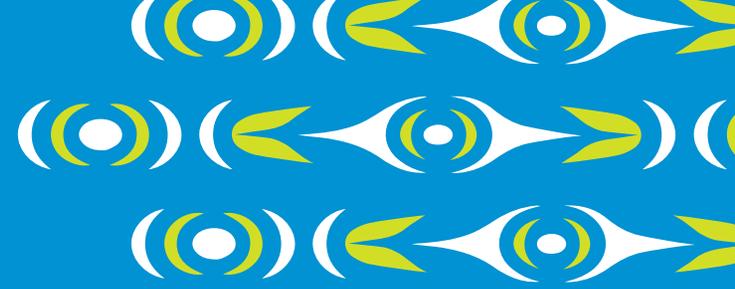
Examples of palliative care supports may include:

- > Western medicines and check-ups to manage pain or other symptoms
- > Counselling and other mental health supports
- > Cultural or spiritual supports
- > Complementary health services like massage and acupuncture

Examples of home-focused palliative care may include:

- > Bathing, dressing and hygiene support (e.g., wound and foot care)
- > Food preparation or meal delivery programs (Indigenous Services Canada/band provided)
- > Shopping, cleaning and home maintenance
- > Supplies and equipment, like raised toilet seats or shower bars
- > Respite care for caregivers

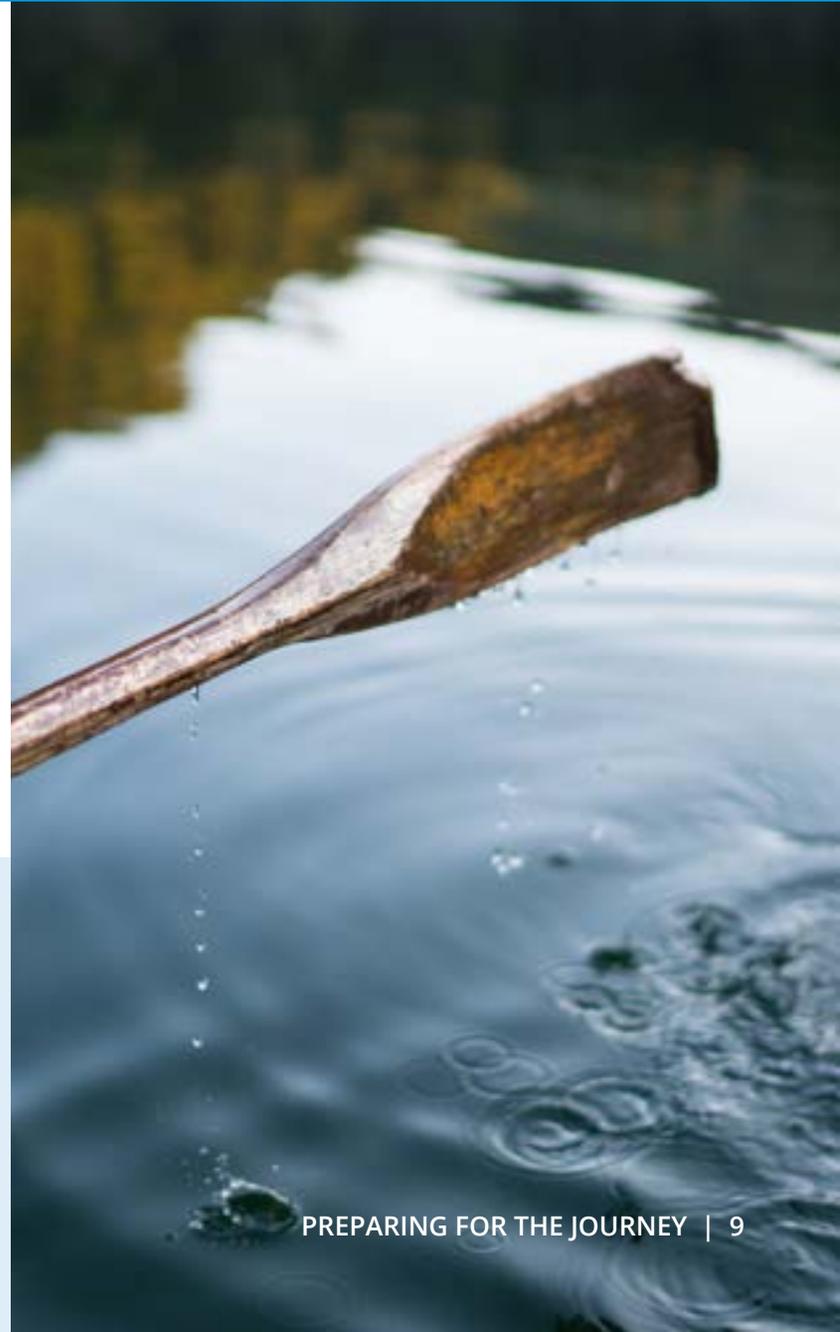
Traditional supports during palliative care



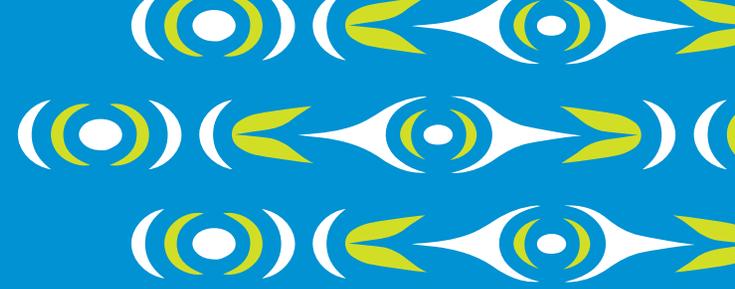
Examples of palliative care that support cultural or spiritual wellness may include:

- > Care from a recognized Elder, knowledge keeper or spiritual leader
- > Cultural or spiritual ceremony and practice (e.g., smudge, brushing, water bath, sweat lodge, prayer, song or dance)
- > Land and water-based traditional activities (e.g., being in nature or gathering plants)
- > Traditional plant-based medicines (e.g., teas, salves or tinctures)

Talk to your health team if you want to include cultural supports and traditional medicine as part of your palliative care plan. Invite your full care team to meet together to better support you. Your care team can discuss how different medicines work, and this will help you make choices that support your wellness.



How to connect with palliative care services



Reach out to your primary care provider or local community health nurse to talk about your needs and learn what options you have. If you do not have a primary care provider, you can call the First Nations Virtual Doctor of the Day program at **1-855-344-3800**

You can also phone your regional health authority Home and Community Care team to discuss what they offer for palliative care. If you need any help finding contact information, call **8-1-1**

Understanding your options



Learning you have a serious illness

When you first learn that you have a serious illness, you may have a range of thoughts and emotions. If you feel comfortable, consider reaching out to a loved one, friend, health care provider or a respected Elder or knowledge keeper for support.

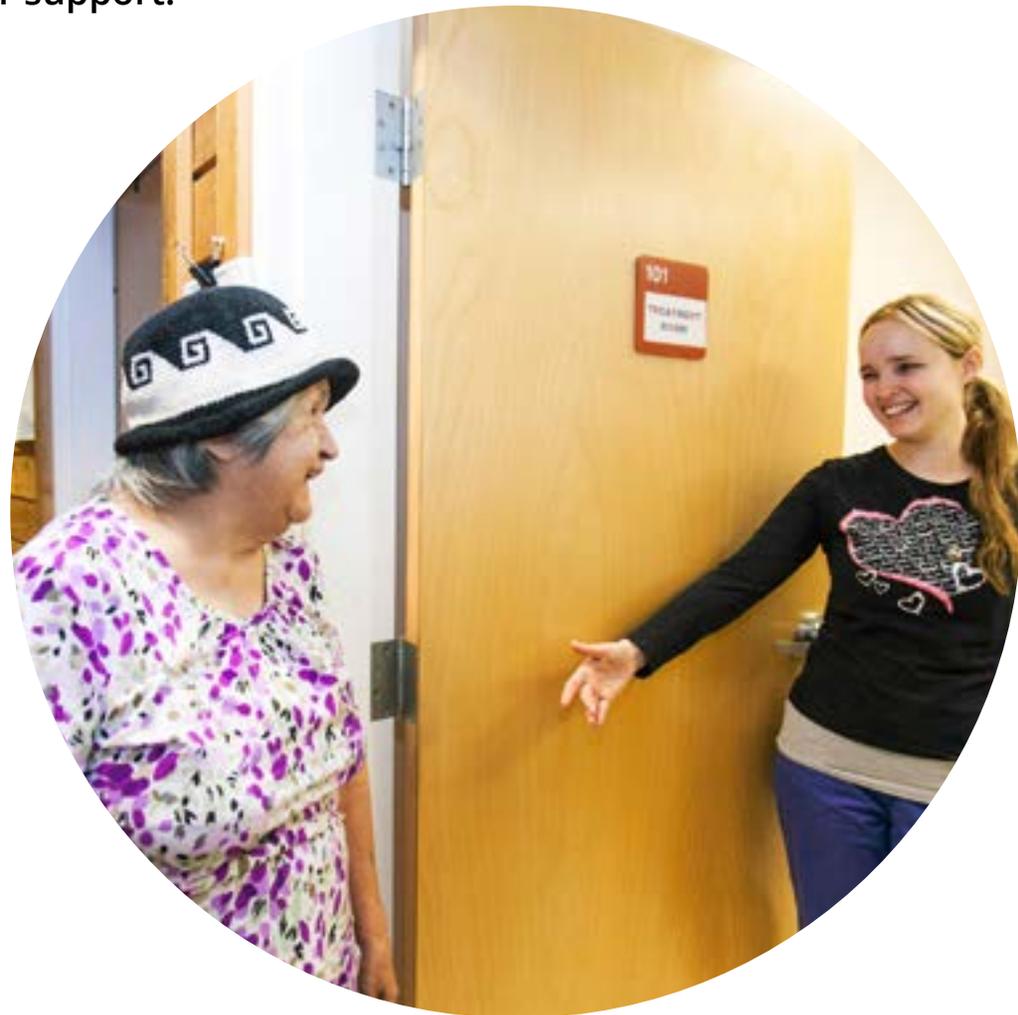
Consider calling mental health support services if you need to talk to someone about how you are feeling. Some supports include:

Tsow-Tun Le Lum cultural supports:
1-888-403-3123

Indian Residential School Survivors
Society Cultural Support:
1-800-721-0066

KUU-US 24/7 Indigenous Support Line:
1-800-588-8717

24/7 BC Mental Health Support Line:
310-6789 (No area code)



Understanding your illness

Understanding your illness will help prepare you and your loved ones for the journey ahead. Trusted health care providers can help share information about what to expect. They can also share information about health care options to support your comfort and quality of life.

It can be helpful to bring a trusted person to appointments with you to listen and remember the information shared.

You might also want to bring a list of questions and ask your care provider if you can record the conversation or take notes. Keep all your information together in one folder or journal. If you have a lot of questions, ask for extra time when booking your appointment.

You have the right to information and answers about your health and well-being.



A trusted health care provider can share information about what to expect when living with a serious illness. Ask as many questions as you need to.

**- ELDER EMILY HENRY,
OCHAPOWACE FIRST NATION**

Questions to ask your health care provider



What is my illness?

Are other members of my family at risk for this illness?

How will my illness change over time? Are there symptoms I should look out for?

Are there any key health care decisions I will need to make?

What are my treatment and pain management options?

What are the side effects from treatment? How can I address them?

Where will I go for my treatments? Will I have to pay for travel or accommodation or are these costs covered?

What services and supports are available in my home and community?

Who will be part of my care team? What does each member of the care team do?

How can my wishes for cultural, traditional medicine and/or spiritual care be met?

Are there mental health supports available for me and my loved ones?

What general supports are available to my loved ones?

Are there any Indigenous navigators, liaisons or other support staff available to me?

Are there handouts, videos or websites that can help me learn about the illness and supports that are available?

What should I expect when I am closer to dying and transitioning to the spirit world? What support might my family and I need?

How to manage multiple concurrent illnesses

Some people may have other illnesses that require various levels of support, ranging from mental and emotional to physical health needs.

It is critical to understand what kind of supports may be needed so that culturally safe resources can be accessed as soon as possible.

Talk to your health providers about what you or a person you are caring for may need in terms of physical, mental, emotional and spiritual support.

“

Remember, your final journey is sacred. It is a time to honour you, your journey and your wishes. You have the right to cultural and spiritual support.

- ELDER JO-ANNE GOTTFRIEDSON,
SECWÉPEMC NATION

Your rights

You have the right to:

- > Be respected as the expert and key decision-maker in your own health: your questions, priorities and concerns matter
- > Receive quality health care
- > Have your wishes heard and respected and to be treated with dignity
- > Have your pain and symptoms treated
- > Be provided with clear information about your health and all treatment options
- > Give consent or refuse consent for any health procedures and treatments
- > Decline or stop treatment at any time
- > Receive health care free of racism and discrimination
- > Receive health care that includes cultural, traditional, spiritual and mental wellness supports
- > Bring a friend, family member or support person to appointments
- > Know that your personal information is private and can only be shared with your consent
- > Ask health providers as many questions as you need
- > Share your priorities and concerns about your health or treatment
- > Ask for a second assessment and opinion from another provider
- > Request your personal health information records

Sharing your experience

If you have any concerns, questions or feedback about any of these rights or your care plan, it is best that you connect with your health care team as soon as possible. A loved one can do this on your behalf if it feels safer for you.

You can also share your experiences through the following feedback pathways in the health care system:

- > Patient navigators and liaisons
- > Health provider regulatory colleges (e.g. College of Physicians and Surgeons of BC)
- > Health authority patient quality offices at **1-888-875-3256**
- > The FNHA Quality Care and Safety Office at **1-844-935-1044** or **quality@fnha.ca**

**Your
wellness**

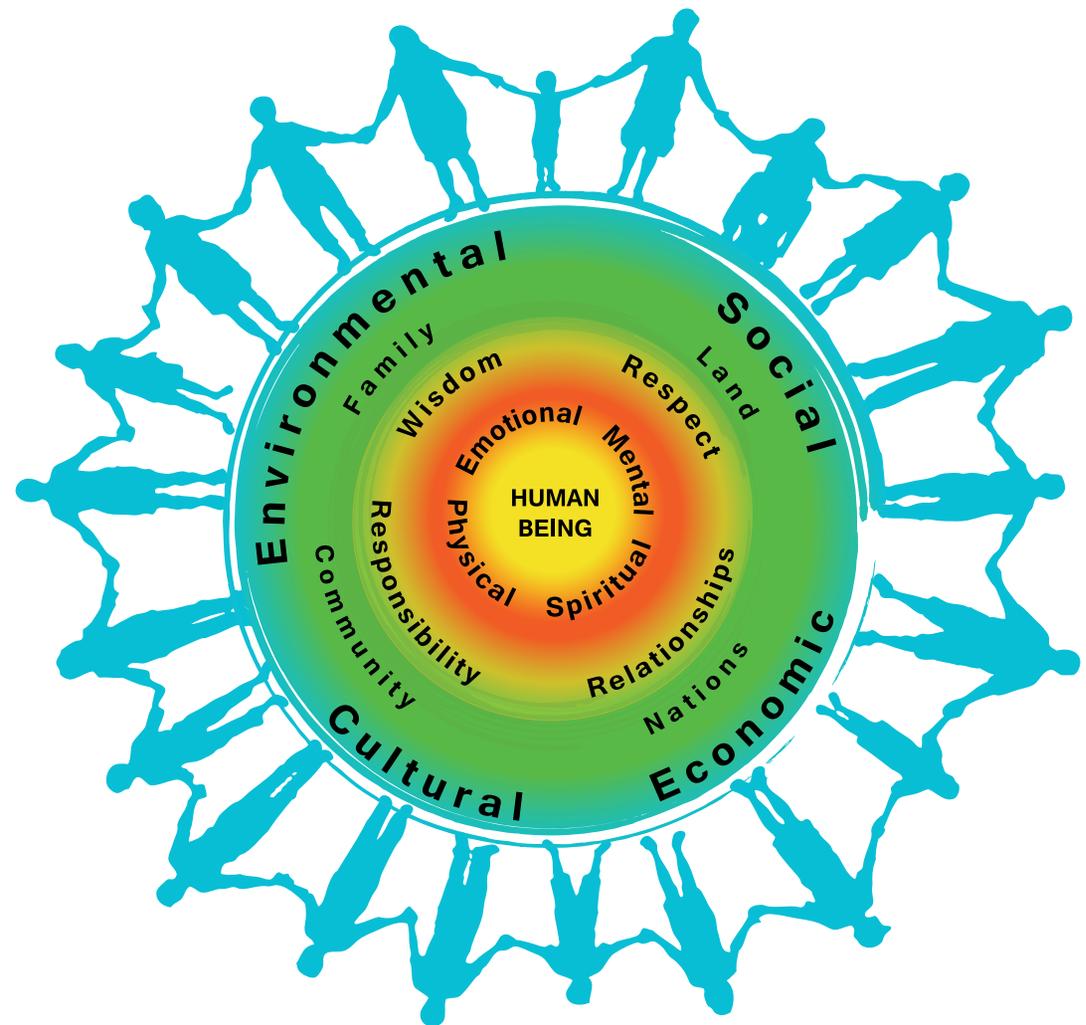


Your wellness

Every person deserves to experience wellness throughout their lives, whether they are experiencing good health, sickness or serious illness. It is especially important to continue thinking about and supporting your wholistic wellness during this time.

Wholistic wellness

Wholistic wellness involves being balanced and well in your whole self, including your physical, emotional, mental and spiritual well-being. This is shown in the orange circle of the First Nations Perspective on Health and Wellness diagram. This diagram shows the different factors that can support your health and wellness. Wellness can be nurtured through a combination of personal decisions and actions as well as supportive people, environments and systems.



Physical wellness

Taking care of your physical wellness is an important part of managing your health and wellness.

Eating well, including foods from the land, and being as active as you are able to, may help keep your strength up for longer. Speak with your health care team about your nutrition, activity and how to use movement aids (such as walkers, canes or wheelchairs) as your body changes. Listen to your body and rest when needed. You can call **8-1-1** to talk to a nurse or dietitian for support too.

Wellness may include taking medications to give you comfort or relief from symptoms. Some symptoms may also be caused by taking medications. Speak to your health care provider about your symptoms and any side effects you are experiencing. If you do not have a primary care provider, you can call the First Nations Virtual Doctor of the Day program at **1-855-344-3800**.

Taking care of your physical body (such as bathing, brushing your teeth or cutting your nails) may become harder to do on your own. Although you may be used to doing things on your own, asking someone to provide personal care can help you feel better. Ask about local home and community care services that may be available to you.

“

Get the rest you require. As you make end-of-life plans, honour your body's limitations. If you can, walk or have someone push you in a wheelchair to see a nice view or to get away from your bed briefly.

- ELDER EMILY HENRY,
OCHAPOWACE FIRST NATION

Finding balance: spiritual wellness

Living with a serious illness and preparing for death is a time when spiritual wellness can be important for some. It can be a period for personal reflection or to newly explore or reconnect with cultural or religious practices. It can be a time to connect with others or to find renewed meaning in life. Everyone's path and beliefs are different and should be respected.

Taking part in culturally grounded practices, protocols and ceremonies can be a helpful way to nurture your spiritual wellness. Spending time in nature and participating in activities that bring you peace can be healing. You may be part of a religious or spiritual group or find comfort in reading religious or spiritual writing, or talking to your ancestors.

Recognized Elders, traditional knowledge keepers, spiritual care leads or staff of religious organizations are all potential people to reach out to, depending on your needs and beliefs.

“

Spiritual support can be a source of comfort at any point in your sacred journey, whether you have just been diagnosed with a severe illness or are closer to dying and transitioning to the spirit world.

Let your loved ones and health care providers know the type of spiritual support you find most comforting. That said, always plan for your present state of health. For example, if the ceremony means sitting for an extended period, consider attending for a brief time. If you can no longer tolerate smudge or smoke, a cedar or eagle fan brushing might bring you similar comfort. If nature brings you solace, and you can't get outdoors, having plants around you may elicit feelings of being outdoors.

- ELDER EMILY HENRY, OCHAPOWACE FIRST NATION

Finding balance: Emotional wellness



Spending time with and talking to people you trust can help you manage the emotions you may be experiencing.

If you feel comfortable, sharing your feelings, concerns and needs allows others to understand and walk alongside you. Try to do things that bring you comfort. Laughter can be helpful at times. Try to surround yourself with people who lift you up. Speak to a recognized Elder, mental health worker or health care provider. Crisis lines are also available and are listed on the following pages.



Mental wellness

Staying mentally well is a key part of your wholistic wellness.

Knowing what to expect and feeling prepared can help. Speak with your health care team for information and support. Keep a notebook with your questions and helpful information. Mental wellness can be nurtured by connection with others and the land. Counselling and medicine can also be helpful for some. If you need additional support for your mental well-being, speak with a family member and your health care team to find resources to support your mental wellness. Resources can be found at the end of this document.



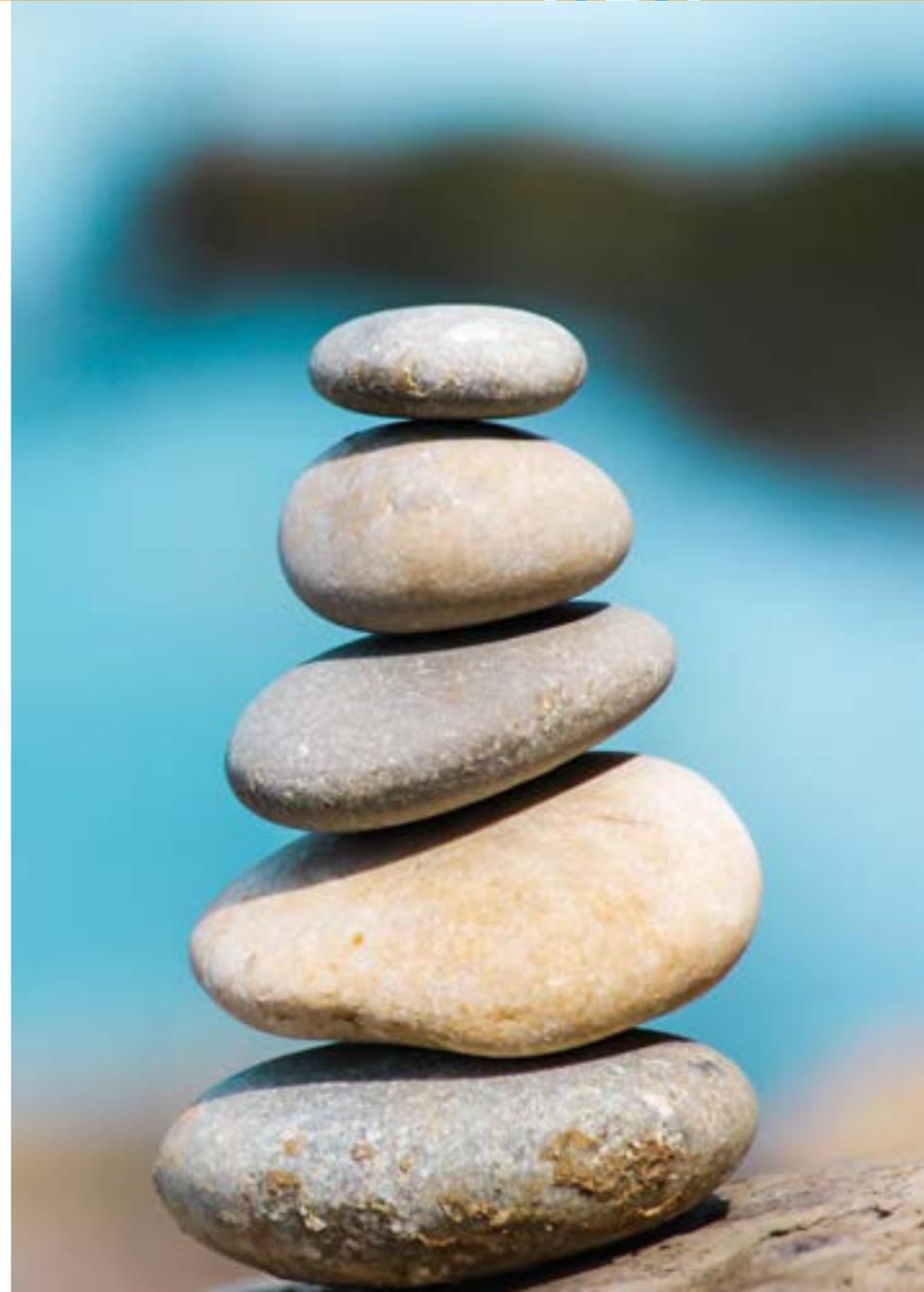
Take time to honour your thoughts and feelings. Remember that you are grieving the most significant loss of all. You are grieving your life. Be gentle and compassionate with yourself. Take time to reach out to healthy, emotionally supportive people. Spending time with and talking to people you trust can help you feel better.

- ELDER EMILY HENRY, OCHAPOWACE
FIRST NATION

Sexual wellness

Traditionally, sexuality was not shameful and as part of First Nation teachings, sexuality meant understanding our bodies' needs and limitations.

Healthy sexuality is part of wholistic well-being. As you experience changes to your health caused by illness, take time for self-care by learning ways to be gentle with your changing body. Your wellness may include maintaining open communication with your partner(s) about your evolving needs. Explore ways to continue to enjoy your relationship(s) through mutual problem solving. Consider reaching out for support to your health care provider or trusted resource person to talk about wholistic sexual health. It is an important time to wrap yourself in love, kindness, and patience in all aspects of your wellness.





Prior to European contact, sexuality was not viewed as taboo. We had elaborate ceremonies celebrating rites of passage (youth to adulthood). Intimacy was simply part of our life and was part of our teachings (e.g., respect for our body). We understood that through a person's life stages, certain needs evolve from sexual intimacy to companionship. This was true as a person aged or when they became unwell. Residential School or Day School (Christian views) taught us that sexuality was taboo.

Today, as we return to our traditional ways, we honour our sexual intimacy as it relates to our life stages, as well as our physical wellness. When a person can no longer maintain sexual intimacy, they honour their bodies and emotional needs through loving companionship.

- ELDER EMILY HENRY, OCHAPOWACE FIRST NATION

Giving back to your community



Some people choose to share and pass down their knowledge and traditions/teachings with peers and younger generations.

The third circle of the First Nations Perspective on Wellness diagram shows the values that support and uphold wellness: respect, relationships, wisdom and responsibility. Sharing your stories, language, knowledge of the land and culture is a way to give back to your community.



**Cultural and
spiritual
supports for
palliative care**



Cultural and spiritual supports and palliative care



Cultural and spiritual supports can be helpful at any point of your journey. There are a variety of cultural and spiritual supports available and it is important to think about which might be best for you.

Examples of cultural or spiritual supports in palliative care include:

- > Care from a well-respected and known Elder, traditional healer, sacred knowledge keeper or other spiritual leader
- > Support from a multi-faith care provider through a health authority
- > Cultural or spiritual ceremony and practice (e.g., smudge, brushing, water bath, sweat lodge, prayer, song or dance)
- > Land- and water-based traditional activities (e.g., being in nature or medicine harvesting)
- > Traditional medicines (e.g., teas, salves, tinctures, bear grease or eagle fans)

Discuss your wishes and decisions about cultural and spiritual supports with your health care provider. It is important to let your doctor or pharmacist know if you are taking traditional medicines to find out if there could be any harmful interactions. They can give you the information you need to make your own health care decisions and help you be safe.

Indigenous cultural and spiritual care contacts:

Tsow-Tun Le Lum

Toll-free: **1-888-590-3123**

Indian Residential School Survivors Society

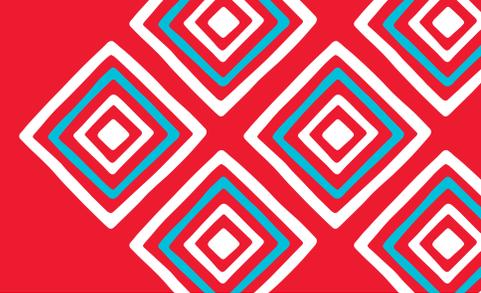
Toll-free: **1-800-721-0066**



The end-of-life for Indigenous people is very sacred. When someone is known to be at their end-of-life, our community, our family and our nations come together in such a sacred way. There are special ceremonies that each region has when someone is at their end-of-life. We all have different values and practices.

- LUCY BARNEY, T'IT'Q'ET NATION

Cultural and spiritual supports and palliative care



Many of the FNHA regional teams have traditional wellness coordinators or specialists. They can be a helpful contact to learn more about local resources and connections. Reach out to the FNHA regional teams to learn more or email info@fnha.ca.

A number of individuals supported by First Nations communities in BC have received Indigenous end-of-life guide training. Indigenous end-of-life guides can provide support for you and your family that respects and honours your physical, mental, emotional and spiritual needs. Guides can support good communication and share helpful information about end-of-life. They can also offer advocacy and personal decision-making support. Guides possess knowledge about the range of medical and non-medical comfort care options available and can help connect you to these services.

Reach out to your local community health facility or health director to ask if an Indigenous end-of-life guide might be near you. For general questions about Indigenous end-of-life guides, contact homecare@fnha.ca.



I think of the comfort of just being at home in their own bed, in their own living room, just being where they want to be, being able to maybe sing a song or have people come in. No matter what territory you're in you like to hear your own spirituality to comfort you in the background.

- ELDER THERESA POINTE CAMPBELL,
(GAUN GAUN E MAUT)
MUSQUEAM NATION

Health authority patient navigation and spiritual care services

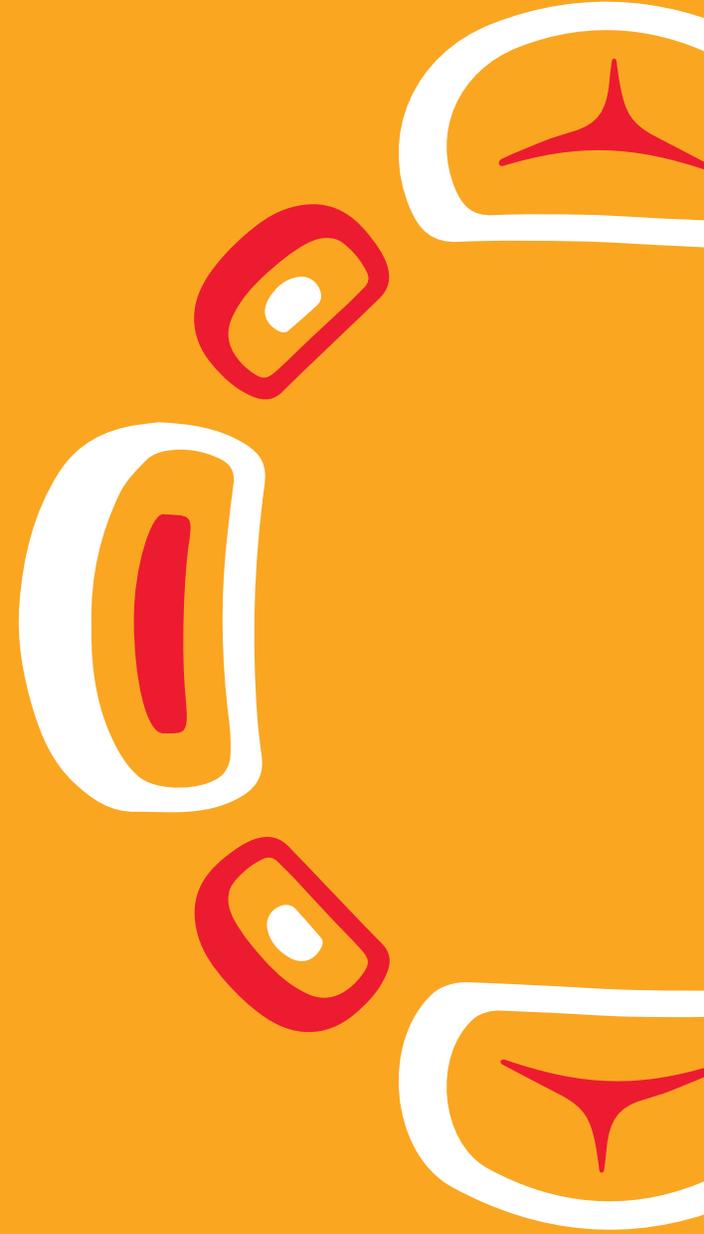
Health authorities offer spiritual care services and many buildings have sacred spaces available for your use. Some have policies in place to support cultural practices like smudging in or outside of hospitals and other health care settings.

Spiritual health professionals are trained to provide comprehensive spiritual health care and emotional support to patients, families and health care staff. You can request the support of a spiritual care provider or religious practitioner specific to your beliefs.

Health authorities also have Indigenous health teams with patient navigators or liaisons who can help you.



Palliative care supports for you



Palliative care supports for you

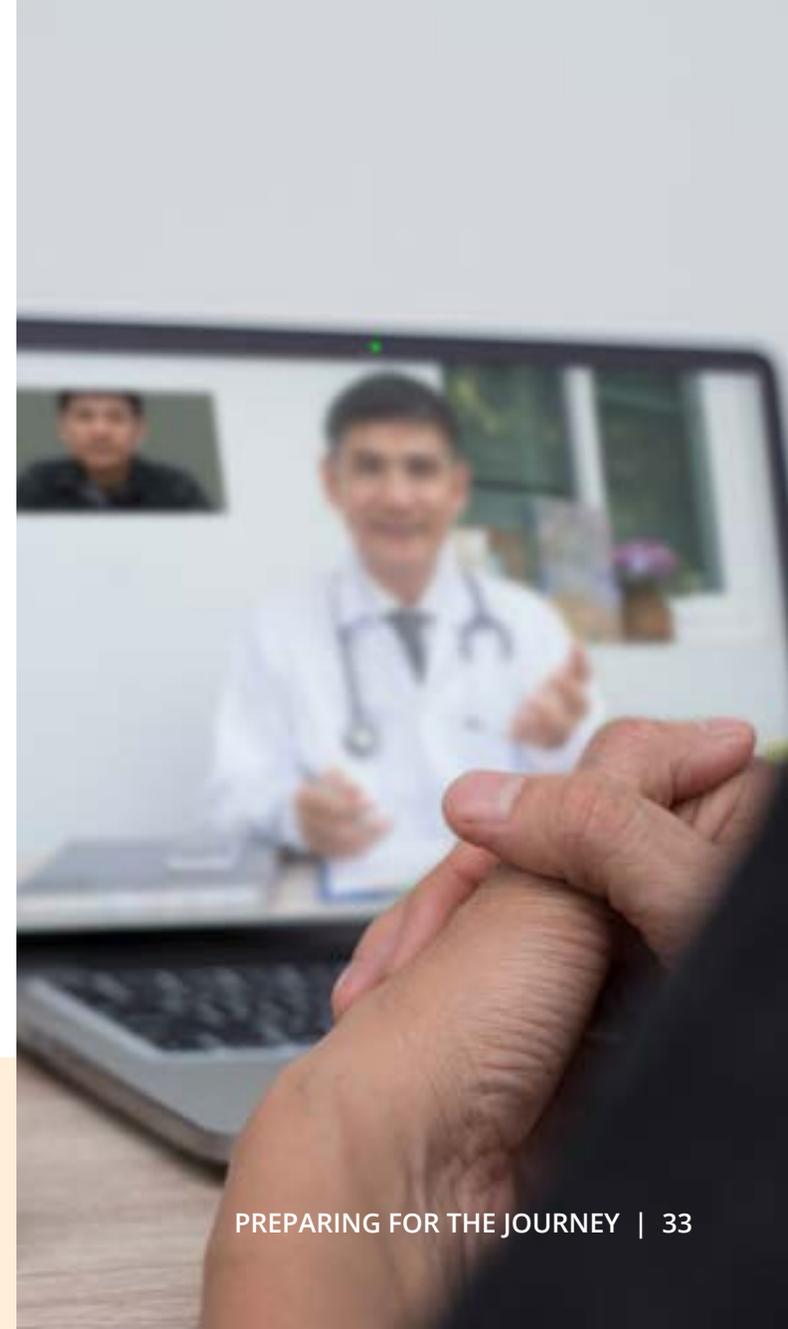
Finding comfort when living with a serious illness and preparing for end-of-life is a personal journey. Many different providers and services are available. Both traditional and western medicine can support a good quality of life that reflects your values and beliefs and provides assistance for your family. Below is an overview of different contacts who might be a helpful fit for you.

Primary care providers

Your primary care provider may be a nurse practitioner or a family doctor. Talk to them about your symptoms, health care wishes and any changing needs. If you do not have a primary care provider, you can:

- > Connect with a health care provider by going to a walk-in clinic
- > Call the FNHA First Nations Virtual Doctor of the Day program
- > Call **8-1-1** to reach a health service navigator who can help you find health information and services

For urgent concerns, please contact **911** and go to a health centre, urgent care centre or hospital.



Cultural and traditional wellness providers

Cultural and traditional wellness providers can be a part of your circle of care.

You may wish to work with a respected Elder, traditional medicine specialist, local knowledge keeper or cultural wellness provider to support your wholistic care needs. If you need help connecting with a provider, reach out to your local Indigenous health facility to ask about options. Talk to your health care providers about decisions relating to cultural supports or traditional medicines. Any potential interactions between medicines can be discussed so that you have the information you need to make health care decisions.



It is important for you to know who your local resources are. Create a list for supports within your community. Build a circle of care.

- ELDER JO-ANNE GOTTFRIEDSON,
SECWÉPEMC NATION



Health care providers and services



Depending on the nature of your illness, you may be working with one or more specialist doctors as a part of your care team (e.g. oncologists for cancer treatments, neurologist for neurological treatments, cardiologist for heart and blood vessel treatments, etc.). It is important for your specialist(s) and primary care provider to work together with open lines of communication. Ask that copies of specialist reports be shared with your primary care provider team. You can also ask for a copy for yourself too.

First Nations community-based services

Each community offers different programs and services. You can connect directly with your community health facility to learn more. Services related to palliative care may include:

- > Community health nurses
- > Home support (can be called care aides, personal support workers, health care assistants)
- > Indigenous end-of-life guides, whose goal is to help First Nations stay in their community should they wish to do so

- > Home-making services (help with chores, housekeeping, etc.)
- > Meal programming
- > Elders, traditional healers, sacred knowledge keepers
- > Medical transportation services
- > Respite care (this gives family/friend caregivers temporary relief from the emotional and physical demands of caring for a friend or family member by providing another caregiver or temporarily housing the patient in a health care facility).

Regional health authority services

As a BC resident, regardless of where you live, you have access to palliative care resources through your local regional health authority.

You can contact your regional health authority's home care team directly to ask about what services are available to you. You can also be referred to the authority's home care support team through your nurse practitioner or doctor.

Contact information for each regional health authority is found on the next page.

Health authority home and community care contacts



Fraser Health:

1-855-412-2121

Interior Health:

1-800-707-8550

Island Health:

South Island: 1-888-533-2273

Central Island: 1-877-734-4101

North Island: 1-866-928-4988

Northern Health:

1-866-565-2999

250-565-2649

Vancouver Coastal Health

1-877-875-1131

Some services that may be available through your regional health authority include:

- > Home care nurses
- > Home support (can be called care aids, personal support workers, health care assistants)
- > Physiotherapists
- > Occupational therapists
- > Mental health workers
- > After-Hours Palliative Tele-Nursing Service
- > Some medical supplies and mobility equipment

Some people wish to remain at home during this stage, and there are various resources available to make it possible for you to do this.

If you have a need for services that cannot be done in a home environment, talk to your health provider about other locations for care, such as a hospital, assisted living facility or hospice.



After-hours palliative tele-nursing service

If you or your family have health-related questions at night (9 p.m. to 8 a.m.), you can contact a nurse by phone to ask for advice on symptoms, caregiver support, equipment issues and more. Your regional health authority's home care nurse can provide you with this phone number.

Benefits programs

First Nations Health Benefits

Some medicines, supplies and equipment may be covered under the First Nations Health Benefits and Services (FNHBS) plan. You are eligible for FNHBS if you live in BC, have a status card and are registered for the program. For more information, please visit: www.fnha.ca/benefits or call **1-855-5454**.

Palliative care benefits

Palliative care benefits are covered through PharmaCare. PharmaCare covers certain medication, medical supplies and equipment that can be organized and offered by your local regional health authority. These services are provided wherever you are living, including at a hospice, at a friend/family member's house or at your home. This benefits program is available to any BC resident who has a serious illness and requires palliative care. Your doctor or nurse practitioner can help you apply for this benefit program.

Health, financial and personal planning



Health, financial and personal planning



Planning can help you to feel prepared and reduce stress

It can be done at any stage, including when you have a serious illness. It is important to think about your health, financial and personal planning needs and wishes. Planning ahead can help make sure that you, your loved ones and your belongings are cared for in a way that is right for you.

Making decisions and sharing your wishes can help give you and your family members' peace of mind. It lets them know how they can best support you. Making these choices can also help you avoid additional challenges, such as missing bill payments.

When it comes to financial planning, you may want to talk to your local bank or credit union, a trusted notary or lawyer and your local social services department to learn more about your options.

There may be a time when you need someone to make decisions about your health and finances.

There are a few important roles to find trusted people for. You can have one person for all roles, or choose a different person for each role. If you do not choose and record people for these roles, someone will be chosen for you according to BC laws and/or in accordance with the *Indian Act*.



A trusted person can be someone who:

- > Knows you well and is willing to take the role
- > Will follow your wishes even if they disagree with them
- > Can make decisions under stress
- > Is trusted to speak as your voice
- > Can be easily contacted
- > Is the age of 19 years or older

You will want to designate someone to take on the following roles regarding your health, financial situation and your estate:

- > Substitute Decision Maker: makes health decisions on your behalf
- > Enduring Power of Attorney: can act on your behalf for financial and legal matters while you are living
- > Executor of your Will: makes sure the wishes in your will are followed after your death
- > Having someone you love or respect available to support you at the end of your life, such as a respected and known Elder or traditional healer



For you, it is an action of self-love; you have done everything to ensure your final wishes are carried out. You are not being selfish; in fact, you are being compassionate. Many people don't plan or let their final wishes be known. You have likely witnessed the outcome when last wishes and wills are not left behind. Therefore, planning is an act of love for your loved one; you haven't left them guessing during their grief.

**- ELDER EMILY HENRY, OCHAPOWACE
FIRST NATION**

Health care planning supported by advance care planning

A substitute decision-maker will make health related decisions on your behalf when you reach a point when this is not possible for you to do.

Talk to your substitute decision-maker about what matters to you, your values and beliefs, and if there are certain types of health treatments you are or are not comfortable with. More information can be found at www.fnha.ca/acp.

Share your advance care planning decisions with your health care provider so they understand what matters to you.

You may want to ask yourself:

What are some simple things that make you happy to hear, see or have near you?

Are there any medical treatments or interventions that you are not comfortable with?

What spiritual, cultural or religious beliefs, practices or ceremonies are important to you?

What brings you comfort?

Do you want to donate your organs?

Financial planning

A power of attorney is someone you authorize to make financial and legal decisions on your behalf while you are alive.

You can talk to your power of attorney about your financial priorities or wishes. You will need to share your financial account information with your power of attorney so they can take care of your financial affairs.

After your passing, the management of your financial matters is done by the executor of your will.





When thinking about financial planning, you may want to ask:

Do you have a list of your financial accounts, common bills (e.g., credit card/electricity/cell phone), mortgage or lease payment agreements and related accounts numbers and passwords?

Do you have any savings or investments? How would you like that money taken care of?

Are there any debts that need to be paid?

Do you have any insurance policies, extended benefit policies, or a pension? If so, what are the account numbers?

Are there any upcoming expenses to be aware of?

Do you have your recent tax history and social insurance number for your power of attorney or executor to file your future taxes?

For more information, talk to your local bank or credit union, local social development department or ask someone to help you with these tasks.

Wills and personal planning supported by executor

When creating a will, it is important to communicate what you would like to do with your assets (such as your savings, house, property, car, etc.) and belongings after you pass away, as well as your wishes for ceremony, protocol or funeral arrangements.

This is also a way to share your wishes about care for others who may be dependent on you, like children, a family member with a disability or pets.

Document your wishes for your funeral, estate (e.g., money, property, etc.) and the care of any dependents in writing in a will and discuss your wishes with your executor. Making these decisions can be difficult, but a will can help to make your wishes clear and reduce stress for your family. With no Will, the Courts or the Minister of Indigenous Services Canada may appoint a person to make all decisions related to your estate. You may wish to consult a lawyer for complex situations, such as if you have custody arrangements, own a business or own property off-reserve. You can make changes to your will with help from a lawyer or notary or cancel a previous will and make a new will.



Do you want certain personal items to be given to specific individuals after you have died? You may want to give some things away while you can. Your traditions may include the distribution of your possessions to the community.

It is best to have your wishes written, so there are clear understandings after transitioning to the spirit world. Taking the guesswork away helps everyone understand that your wishes are being carried out.

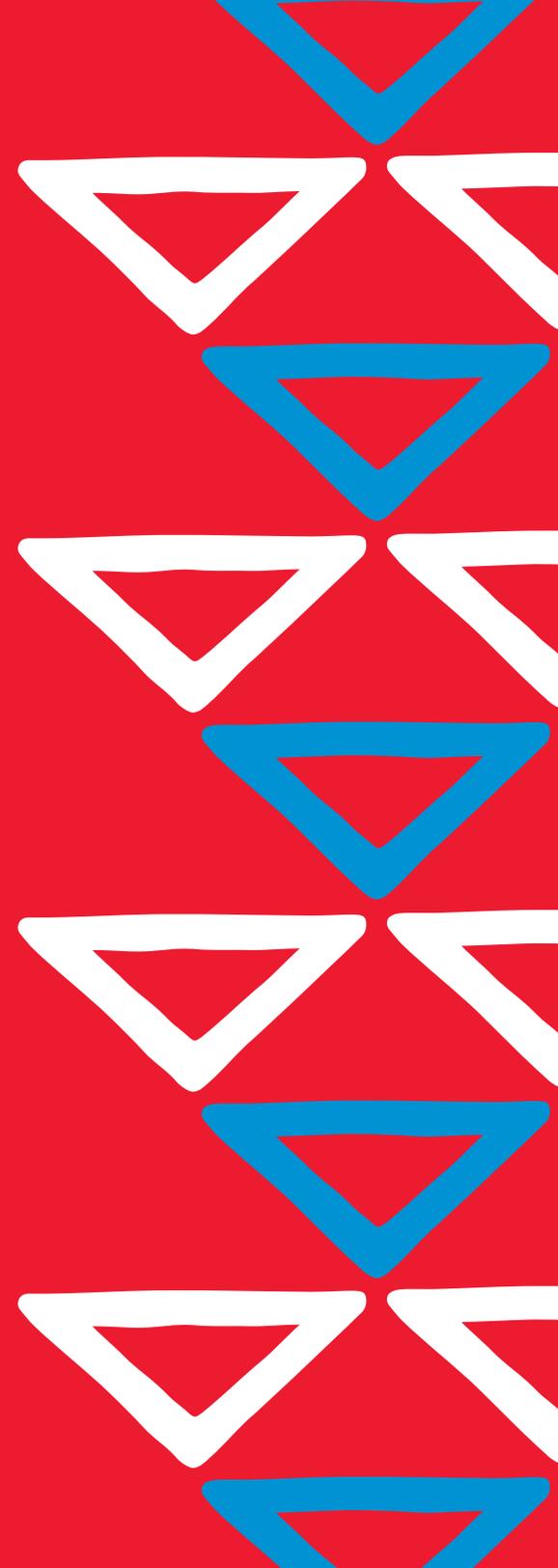
**- ELDER EMILY HENRY, OCHAPOWACE
FIRST NATION**

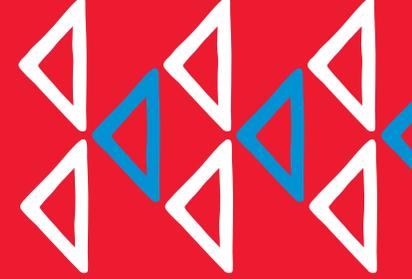
Considerations when creating your will



- > A will needs to be in writing. It can be written by you (perhaps by filling out forms from a will kit, many of which are available online) or with the writing and help of a notary or a lawyer. A will needs to be signed and dated by you and two adult witnesses who should not be people receiving an inheritance from you.
- > Name who you would like to be your executor in your will.
- > List any wishes around ceremony, body preparation (burial or cremation) and funeral service arrangements that you might have.
- > Communicate who you would like to take care of any dependent children or family members and any pets and specific wishes about their care.
- > List any savings, property and belongings and provide names and contact information for who you would like to inherit these. List any debts as well.
- > List any insurance policies you might have and the people who you would like to inherit your insurance (their names should be listed as beneficiaries). Keep in mind that insurance money typically does not form part of a will, and instead, is distributed in accordance with what the insurance policy states.
- > Keep your will in a safe place (safety deposit box, bank office, with a trusted person) and tell your executor where to find it.
- > There are usually some costs involved in making/getting a will.

Personal grief and loss





Personal grief and loss

Grief is a strong emotion that you may experience at any time in your life such as during and after a loss, or a change. You might experience grief after receiving a certain health diagnosis or as you see changes in your health over time. As a friend or family member, you may experience grief when someone you know is having these experiences.



I believe that our grief is really about love – the love we have for people. It is important to embrace it and allow the grief to have its place.

Some grief lasts a lifetime, the way we relate to it changes.

- NOLA JEFFREY, TSIMSHIAN AND
COAST SALISH ANCESTRY

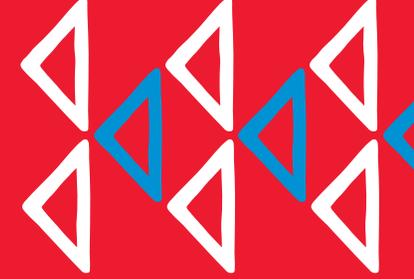
What does grief look like?

You cannot predict how grief might make you feel. You may feel a range of emotions. There is no right or wrong way to experience grief. Each person experiences grief and loss in their own way with no time frame.

Grief can be felt in the mind, body, heart and spirit and may include:

- > Difficulty eating or sleeping
- > Memory loss
- > Confusion
- > Irritability
- > Body shakes
- > Upset stomach
- > Worry, anxiety or panic
- > Crying, guilt or anger
- > Sadness or depression
- > Difficulty focusing or making decisions

Healing journey



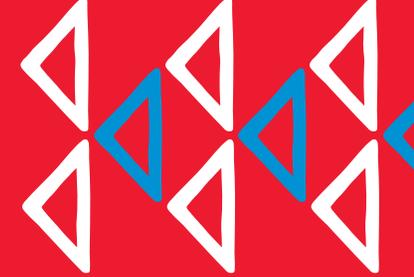
You (an individual with a serious medical illness or family/friends of that individual) may experience ups and downs along your healing journey.

You may have stronger emotions during holidays, special events, family gatherings or with another loss. Even small unexpected things, like a sound, smell or song may remind you of a loss of a loved one. Healing involves taking care of your heart, body, mind and spirit and allowing yourself time to grieve.



I encourage families to turn their fear and anger into a prayer and a song, in our cultural ways.

- ELDER MIKE KELLY,
SHXW'ÖWHÁMEL FIRST NATION



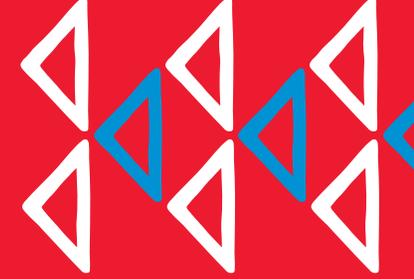
Some things that might help could include:

- > Speaking with friends or family
- > Writing in a journal
- > Walking in nature; getting out on the land
- > Mindfulness activities such as breathing exercises
- > Crafting or creating art
- > Honouring a loss with an event or action
- > Making time for reflection and gratitude
- > Sharing your story
- > Using laughter as medicine
- > Setting wellness goals or intentions

Culturally grounded protocols and practices for healing may vary between people and communities. Some examples include:

- > Cedar brushings
- > Speaking with an Elder
- > Ceremony
- > Connecting with the land and water – e.g. spirit baths
- > Sweat lodges
- > Smudging

Myths about grief



Myth

Truth

Grief is always felt physically.

Grief can be felt in many ways – mentally, emotionally, physically and spiritually.

Grief should not last more than one year.

There is no timeline for grief. Feelings of grief might come and go.

Feeling or showing grief is a sign of weakness.

Thinking about and sharing your feelings with someone you trust might help you to heal and recover from grief/loss.

Not crying means you are not grieving.

Everyone deals with grief and loss in their own way and at their own speed. You can grieve and not cry.

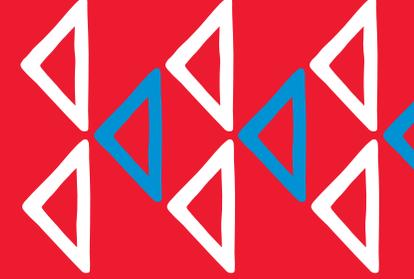
People who are grieving need to be left alone.

Family and community support may be helpful and talking about what you need can prompt others to support you in different ways.

Feeling happy means you are not grieving.

Laughter is medicine. You can laugh and still be in the process of grieving. Having times of happiness does not mean that you do not miss who you have lost.





Getting support

Doctors, nurses, counsellors, Indigenous end-of-life guides, mental health and wellness workers, Elders, spiritual care and cultural support providers are all examples of people who you can reach out to for support.

Crisis lines and emergency services are available. Many telephone lines are open 24 hours a day to offer support whenever you need it.

Know that you are not alone. Be kind and patient with yourself. Help from a counsellor, support group or harm reduction services can help to support your health and wellness.

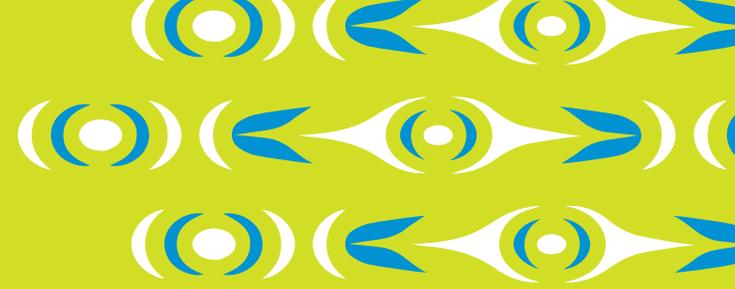
Reach out to your primary health care provider, local First Nations health facility or Aboriginal Friendship Centre to learn more about services that might be available to you.



Talking with children and youth



When to start the conversation



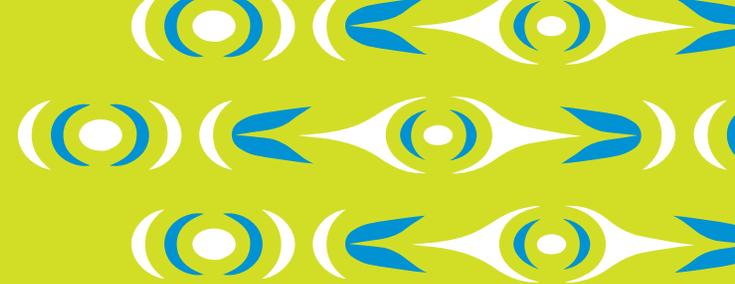
Talking with children and youth about what you are experiencing might be something that you are thinking about.

Talking to your children at an early stage may be helpful for both yourself and for them. Ultimately, this is a decision that belongs to you.

Children and youth, just like adults, need time to understand and process their thoughts and feelings. Some children and youth may find it helpful to talk and have the space to ask questions.



Approaching the topic



Trust your intuition about how to best approach the topic of what is happening to you with children and youth.

There is no one right way to talk about it, but here are some ideas to consider when talking to children and youth:

- > Talk together in a safe, familiar and comfortable place with lots of time available.
- > Share information about what to expect and encourage questions. Find a book from the library or share a story.
- > Connect back with them to see what they understand.
- > Communicate your love and care for them and ask them what they need to feel safe and supported.
- > Let them know that support is available if they need someone to talk to and that you would be happy to help them find that support if they wish.
- > Share your feelings and remind them that they may experience a range of emotions. Ask about how they are feeling and encourage open and regular sharing of emotions.
- > Offer some ideas of things that can support the body, mind, heart and spirit. Model and participate in wellness activities with them.
- > Focus on their strengths, resiliency and what is in their power to control.
- > If helpful, invite a respected and known Elder, traditional healer or sacred knowledge keeper to support discussions with them.



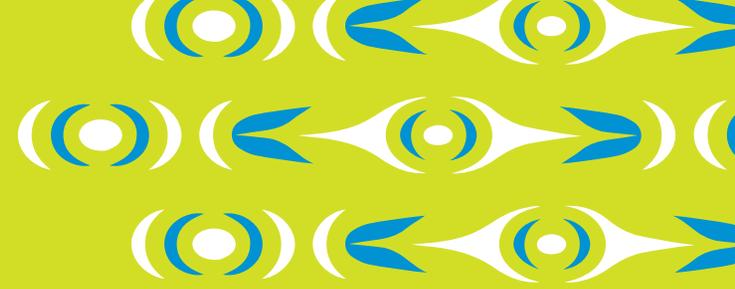
My husband passed away when our children were eight years, four years, three years and three months old. I was 30 years old and a widow with four small children. I was told over and over to 'be strong for my kids.' So I listened to what I believed they meant. I cried at night when the children were asleep. I cried in the shower. Never in front of the children.

Fast forward about three or four years. I was in a counselling session. The counsellor asked me about my grief and to describe what I did. So I told her about not crying in front of the children. I was so proud of myself to inform her of that. She looked at me and said 'Rachael, if you don't cry in front of your children how will they learn to grieve?' I was stunned.

The next time I needed to cry I did so in front of my children. They were bewildered. Asked me why I was crying? I told them I miss your dad so much. They all surrounded me and were comforting me. The older ones said 'we thought you didn't care dad died, that you didn't love him!' I was shocked! We then had a family discussion about missing their dad, loving him and we all had a good cry together. From that day forward we grieved our loss together.

- RACHAEL ALEXANDER, TSAL'ALH FIRST NATION

Basic information to share



Below are some examples of topics to discuss with children and youth so that they can understand what is happening and be prepared. Additional resources are listed at the end of this brochure.

- > Information about the serious illness.
- > Information about the treatment, its possible side effects and how this might affect the household (such as needing to travel for health care, take time off work, see different care providers, being sick or losing energy during treatment, having less time and attention from the adult with the illness).
- > Information about transitioning to the spirit world (such as what the physical process can look like, and what happens to the body before and after passing away).
- > Information about how your cultural beliefs, ceremonies and traditional practices may be involved at this time.
- > What your family can expect afterwards, such as who will take care of them, where they will live, trusted adults they can reach out to for support and what will happen to their things.

Keeping up routines

Keeping routines and structure can be helpful for children and youth as they journey with you through these life changes. Offering the opportunity for children and youth to connect with traditional and cultural activities such as smudging, brushing, berry/plant gathering, drumming or dancing might help with mental and spiritual wellness.

It is also helpful to maintain things that children and youth are familiar with, especially friendships, play, relationships and connections to community.

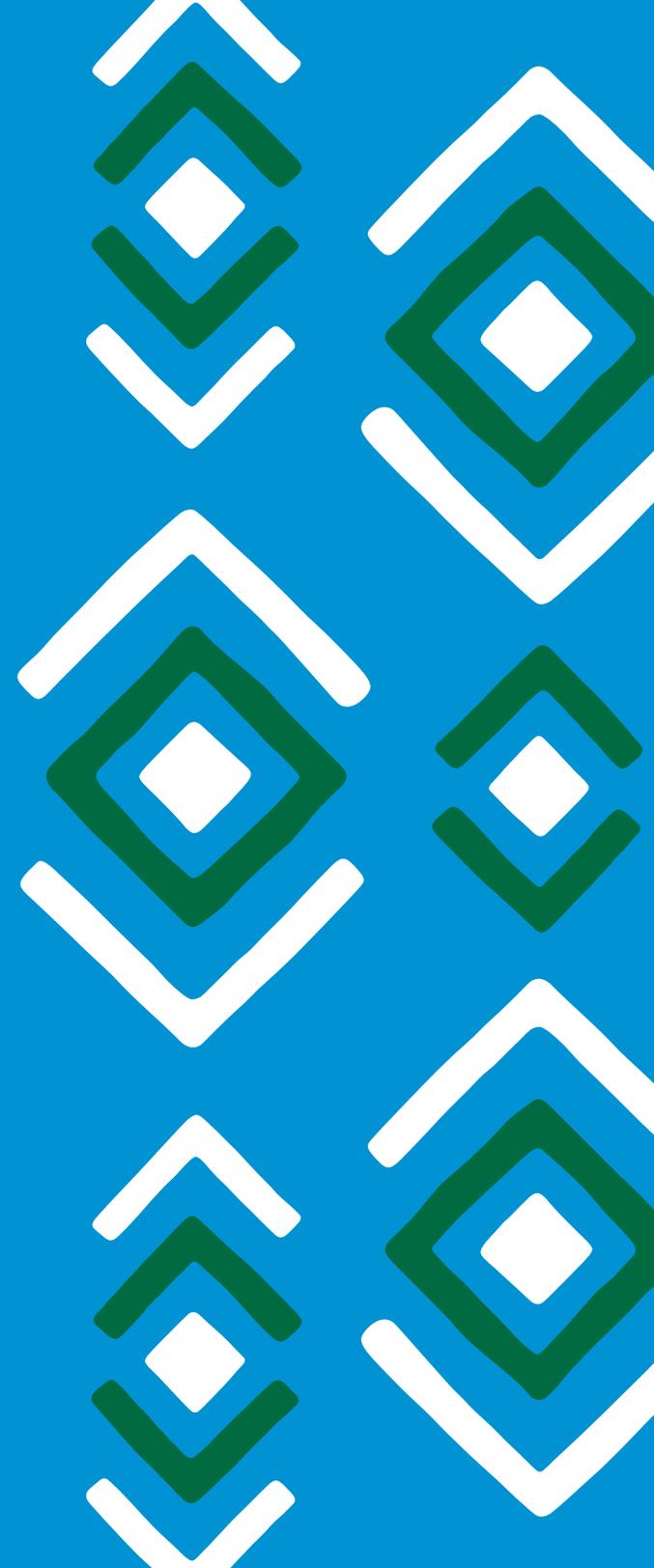
Learn more: www.KidsGrief.ca



Children are sacred and they deserve openness, honesty and protection. Children can be left with wandering thoughts and may not understand the final journey process. Keep it real. Be creative. Encourage the grieving process in a holistic way.

- ELDER JO-ANNE GOTTFRIEDSON,
SECWÉPEMC NATION

Being a caregiver



Being a caregiver

Caregivers provide help and care to family or friends.

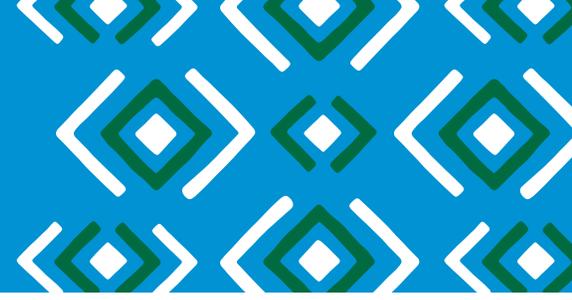
Care can come in many forms and can be hands-on and physical, emotional, organizational or practical. As a caregiver, you are a vital part of the care team. You can ask to be a caregiver or you may be asked to help out. If you are asked to be a caregiver, it is important that you feel comfortable with this role and responsibility. It is a personal decision.

As a caregiver, you may be involved with:

- > Accompanying the person who is ill to the doctor
- > Planning and advocating for care
- > Grocery shopping, cooking, feeding
- > Helping with household chores and maintenance
- > Dressing and bathing
- > Giving traditional medicine or Western medications
- > Monitoring and helping to report pain, symptoms and side effects of medicine
- > Helping with legal and financial issues
- > Updating family and friends
- > Providing cultural or spiritual support



Things to consider when doing caregiving work



Talk to the person you are caring for about their:

- > Wishes and what roles they see you having as their caregiver
- > Health priorities and where they ideally see themselves receiving care as their illness advances (e.g., at home, in a hospice, in long-term care, at a hospital)
- > Need (or not) for advocacy support to help share their wishes with their health care team and other family members or friends
- > Boundaries that they would like respected (e.g., their comfort level with help being bathed or comfort level with handling of personal items)
- > Other friends and family members to reach out to, to coordinate help

Share with the person you are caring for what you feel comfortable doing and not doing and how much time or availability they can expect from you.

Being a caregiver

Ask for help from health care providers to:

- > Learn caregiving skills like bed-baths, toileting, positioning in bed, mouth care
- > Get any needed equipment (e.g., hospital bed, bath chair, walker)
- > Understand what to expect as the person's illness advances and when end-of-life is nearing
- > Learn about support services, like respite care, that might be available near you
- > Make a schedule for yourself. Include time for rest and your own personal care. This will help you stay well

“

The final journey is filled with tender moments. It is an honour and privilege to share and be a part of someone's final journey. Be gracious. Be humble. Be kind.

- ELDER JO-ANNE GOTTFRIEDSON,
SECWÉPEMC NATION

Honouring emotions

Making the space and time to honour emotions and feelings is an important part of caregiving, to support yourself and the person you are caring for.

Things to consider as a caregiver:

- > If the person you are caring for wants to talk about things they have never spoken about before, or if they need to cry, it is important to let them do it. Acknowledge their feelings and thank them for trusting you with them.
- > Try not to take anger personally. If the person you are caring for is having a hard time, they may be angry. You are not to blame. They may be upset because they feel unwell or are grieving.
- > Talking or replying is not always needed. Listening and staying quiet can let thoughts and feelings be. Just being there can be a comfort.
- > Kind words, caring gestures (like making a cup of tea) or a gentle touch can let someone know they are not alone.
- > Paying attention to body language is important. If the person who you are caring for is in pain, they might frown or have their knees curled up. Offer medicine or help them to change their position for comfort.
- > Practice self-care if what is seen or heard is hard on you.

Self-care as a caregiver

To care for someone else in a good way, it is important to take care of yourself. To take care of your own health and wellness, try to:

- > Eat regularly and drink plenty of water. Try to cook with whole foods such as fruit, vegetables, beans, grains, eggs, lean meats, fish and wild game. Cooking large batches of food and freezing some for future meals is a useful strategy.
- > Exercise regularly. Walking is a great way to get started and can help you maintain your energy levels and reduce stress.
- > Connect with nature, culture and people who you trust. Making connections with respected and known Elders, knowledge keepers and healers may be helpful for you.
- > Get enough sleep and rest. Make space to take breaks and have quiet time.
- > Reach out to trusted friends, family or a mental health provider, like a counsellor, to talk about your experiences and feelings, if this feels right for you.
- > Make time for personal care needs, like haircuts or regular medical appointments.
- > Communicate your needs and ask for help, including with navigating the health care system, your feelings of grief, financial support and any questions or concerns that you have



It is really important to make sure that we are doing our own self-care, getting rest and nurturing ourselves. One person cannot do it all by themselves.

- NOLA JEFFREY, TSIMSHIAN AND
COAST SALISH ANCESTRY

Signs that you need extra support

Reach out right away to the health care team of the person who you are caring for if you are feeling:

- > Worried about the person's care or symptoms
- > Need more support or knowledge to provide care
- > Need help with equipment
- > Often tired, anxious, overwhelmed or sick
- > You do not have the time to care for your own needs
- > Angry or frustrated towards the person you are caring for
- > The environment is not safe for your or the person you are caring for

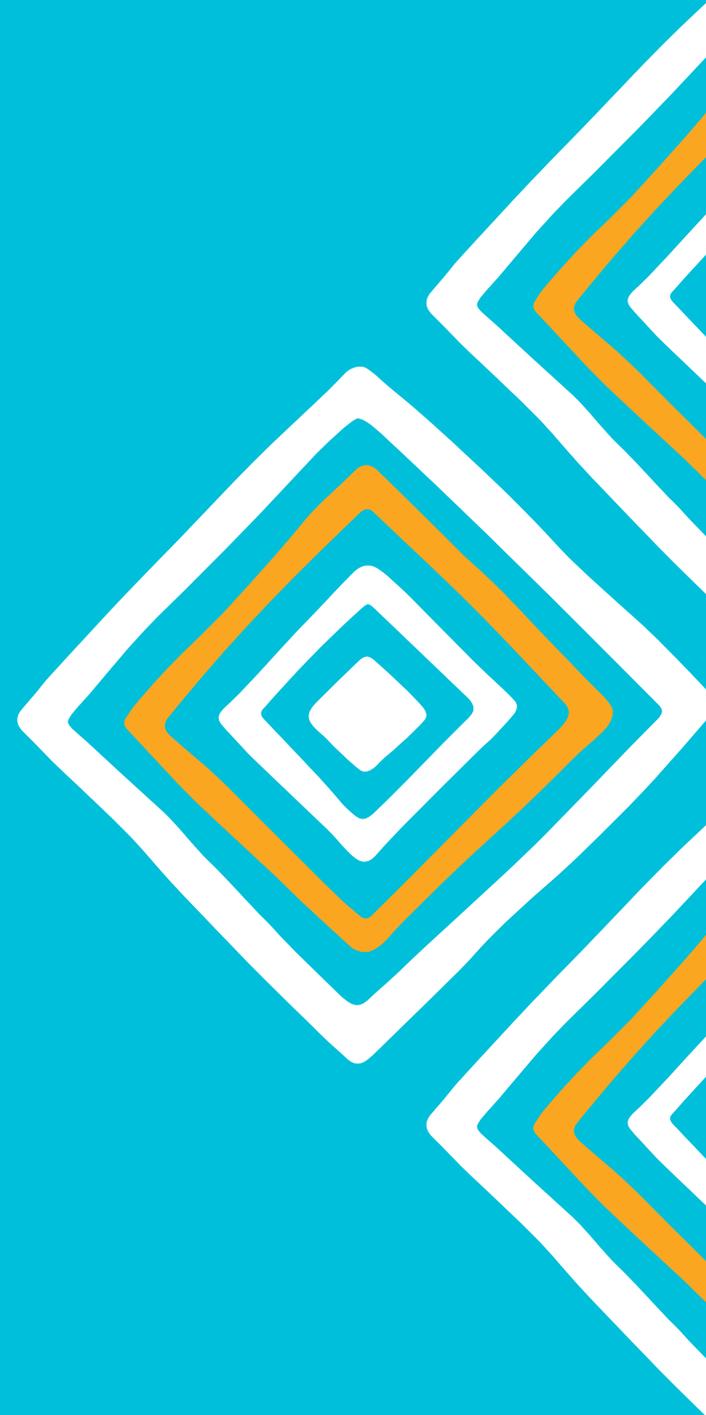
At some point, a person with a serious illness will likely need care all day and night. If the person is staying at home, make sure you have helpers to share and coordinate the care. Talk to the person's health team to learn about supports and services that may be available. Additional help can be paid and unpaid.

Caregiving for a friend or family member with a serious illness can involve a wide range of experiences and emotions. Being patient, open and kind with yourself and the person you are caring for can help support health and wellness for you both.

To learn more:

Family Caregivers of BC
www.familycaregiversbc.ca
1-877-520-3267

**When the
end-of-life
is near**



When the end-of-life is near



When a loved one nears the end-of-life, a number of changes to the body may occur.

Sleep and energy changes

A person may sleep for longer periods, have difficulty waking and lack energy to speak or do other activities. They may withdraw from activities and their awareness level may change. Before passing away, they may go into a deep state of unconsciousness called a coma.

What can family or friends do? Sitting with them can provide comfort. Speak softly and naturally because they can probably hear you. Hearing is the last sense to be lost. Do what feels right: hold their hand, sing, read, play music, share memories and/or pray together.

Eating and drinking changes

A person near the end-of-life may not be hungry or thirsty. Food and fluids are no longer useful. It is natural to want to feed someone, but at this stage, food and fluid may not be what their bodies need and could make them feel worse. Swallowing can also become difficult.

What can family or friends do? Keep that person's mouth moist with a damp cloth and apply moisturizer or lip balm to dry lips. Provide food and drinks when asked. Make sure they are awake and sitting up to swallow. Stop if they start to cough or choke. Do not force them to take food or fluids.

Changes in going to the bathroom

You will notice less urine and stool. The urine will become darker in colour (like tea) and they may lose control.

What can family or friends do? Put an absorbent pad under them and change it as needed. Keep the skin clean and dry. This will also support the dignity of your loved one.

When the end-of-life is near



Skin changes

Hands, arms, feet and legs can become cold, hot or change colour. The colour of the skin may become mottled or blotchy. The face may become pale. It tells us the body is sending blood to only the vital organs to conserve energy.

What can family do? Keep the person warm with soft blankets. If they keep removing the blanket, use a light sheet, a cool moist cloth on the forehead and/or provide a fan. If you think they have a fever and are uncomfortable, medication might help to lower their temperature.

Breathing changes and congestion

The person may take shallow breaths with periods of no breathing for up to a minute or so. They may experience periods of rapid, shallow panting. Sometimes there is a moaning sound with breathing. This moaning means the vocal chords are relaxed. There may be loud gurgling sounds inside the chest from not swallowing saliva. This can be upsetting to hear but is not uncomfortable for them.

What can family or friends do? Oxygen is not useful, unless the person previously required oxygen for an illness. Reposition them on their side (using pillows underneath

one side of the body can help, as they may not be able to maintain this position by themselves) so their head is turned, or raise the head of the bed. Suction equipment will not help and could cause discomfort. Sometimes medication can help. It is good to ask questions to health providers for more information.

Restlessness and confusion

The person might pull at the bedsheets or clothing and may even try to get out of bed. They might not know where they are, who you are or they may not make any sense when talking. This can be distressing for family and friends to witness.

What can family or friends do? Confirm that the person is not in pain, too hot or too cold, or needs the bathroom. Make the person comfortable. Create a calm environment and speak in reassuring tones. Accept what they are saying and avoid arguing. Their experience is real to them. Avoid restraining their movements. Provide light massage, play calm music, drum, sing or pray. Sometimes medication and traditional medicines can help.



I envision our ancestors come in a big canoe to collect our loved one to bring them to the other side. They are not alone.

- NOLA JEFFREY, TSIMSHIAN AND COAST SALISH ANCESTRY



Letting go of someone you know and love



Letting go of someone you know and love is very personal. There are many different ways to do it. If you need to talk with someone, let a health provider know.

Also, let your health provider know if the person wants any specific practices or protocols so that this support can be provided. Even though you know the person is dying, it may still feel unexpected when they pass away. There is no need to rush. Take the time you need to say goodbye.

If you would like ongoing grief support, contact your health care provider or local Hospice Society. Your community centre might also have loss and grief support.

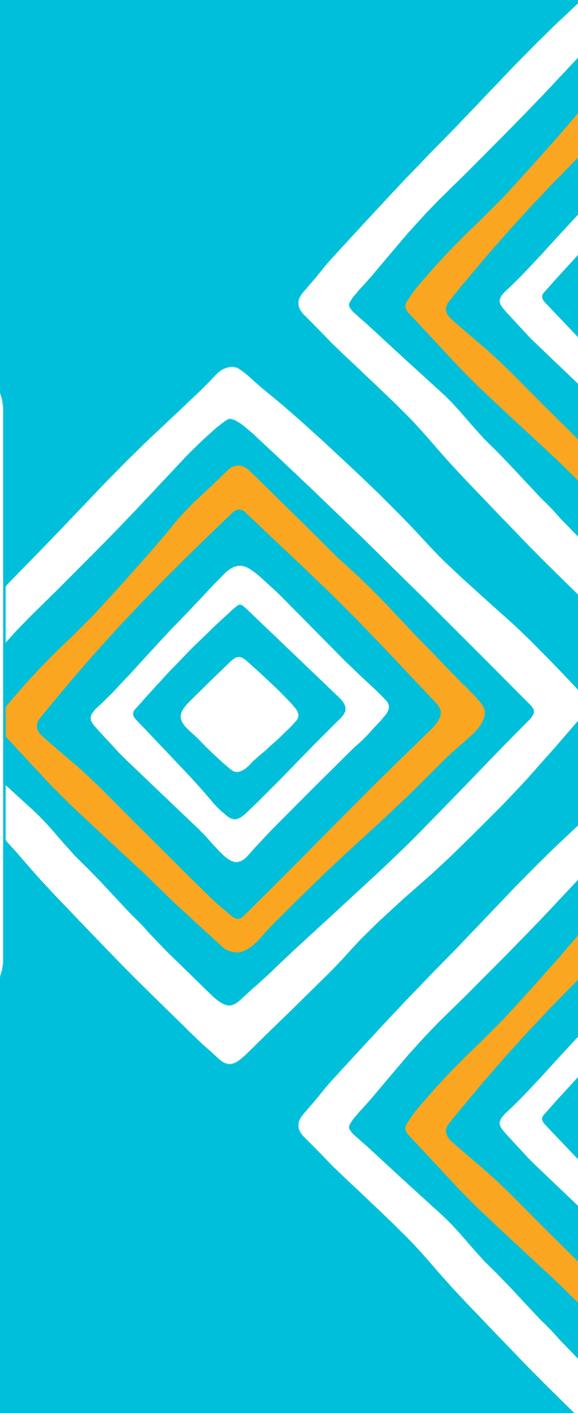




“

Death is like birth—a transition. When our son was born he was grey. When the doctor touched him, he filled with breath. I could see the life (energy) come into my son and his colour changed. The opposite thing happened when my mom took her last breath – you could see her colour leave. As she transitioned to the other side, you could actually see her spirit leave. Both experiences were beautiful and amazing.

- NOLA JEFFREY, TSIMSHIAN AND COAST SALISH ANCESTRY



Summary of resources and contacts

1-855-344-3800

First Nations Virtual
Doctor of the Day program

8-1-1

Registered nurse or registered
dietitian with HealthLink BC

1-855-550-5454

The FNHA Health Benefits Program

1-888-590-3123

Tsow-Tun Le Lum Cultural Supports

1-800-721-0066

Indian Residential School Survivors Society
Trauma-Informed Cultural Support

1-800-588-8717

KUU-US 24/7 First Nations and
Aboriginal Crisis Line Support

310-6789

(No area code)

24/7 BC Mental Health Support Line

1-800-663-1919

Access Pro Bono

1-866-577-2525

Aboriginal Legal Aid

1-800-663-0343

Society of Notaries Public of BC

To access online
resources please visit
the QR code below:



[FNHA.ca/Documents/FNHA-
Palliative-Care-Online-Resources.pdf](https://fnha.ca/Documents/FNHA-Palliative-Care-Online-Resources.pdf)

[FNHA.ca/Cancer](https://fnha.ca/Cancer)



First Nations Health Authority
Health through wellness

**BC
CAN
CER**

Provincial Health Services Authority

